

*Education and Training in Autism and Developmental Disabilities*, 2017, 52(3), 240–251

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## Early Intervention in Autism Spectrum Disorder: Concerns and Support of Portuguese Mothers

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*Abstract: Families of children with autism spectrum disorder (ASD) face a series of daily challenges, from which emerge a number of concerns that are inherent to the reality of living with a child with ASD, as well as the demand for formal and informal supports that are required for these families. This study's main objectives were to: (1) identify and consider the concerns of Portuguese mothers with children with ASD; (2) identify and consider the required forms of support that those mothers need; and (3) understand if the support networks that are given to these mothers are adequate in face of their concerns. Results showed that these mothers hold concerns and support that are consistent with most of the scientific studies in this area. Results also indicate a greater demand for formal support throughout the life of the child with ASD, rather than informal support. The inadequacy of support provided by the primary health care system is highlighted by the mothers, especially at the initial stage and in the diagnostic process. Finally, results suggest the adequacy of specialized formal support, especially in the context of early intervention, although mothers complain about the amount of existing supports, as well as the frequency and duration of sessions provided by therapeutic services and early intervention programmes.*

### Early Childhood Intervention in Portugal

*Early Childhood Intervention National System (SNIPI)*

SNIPI is an organized group of institutional entities, that act to ensure development conditions in education, and in the health and social system, for children aged 0 to 6 years who have changes in body functions or body structures, with severe risk of developmental delays, and their families (Decree-law No. 281/09, of October 6, 2009).

With regard to eligibility criteria, according to Decree-law No. 281/09, of October 6 (2009), children between 0 and 6 years and their families are eligible for support under the SNIPI if they present the following conditions: (1) changes in body functions or structures; or (2) high risk of developmental delay. All children in group 1 and group 2, who have four or

more factors of biological and/or environmental risk, are eligible for access to SNIPI.

SNIPI works by joint representative structures of the Ministries of Labour and Social Solidarity, Health and Education, in close collaboration with families, and is coordinated by the Coordination Committee of SNIPI. The aims of SNIPI are to: a) ensure the protection of children's rights and develop their skills through Early Intervention (EI) actions throughout the country; b) detect and flag all children at risk of changes or with effective changes in body functions and structures, as well as children with serious risk of developmental delay; c) intervene according to the needs of the family, in order to prevent or reduce the risk of developmental delay of the child; d) help families in accessing services and resources related to health, education and social systems; and e) involve the community by creating articulated mechanisms of social support (Decree-law No. 281/09, of October 6, 2009).

EI practices aim to promote and ensure the participation and social inclusion, as well as the quality of life of these children and their families, for which access and response must be universal. To ensure and implement the

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principles adopted by the SNIPI, there are EI local teams.

EI local teams operate at the level of municipalities or parishes and are composed of doctors, nurses, psychologists, therapists, social workers, and kindergarten teachers who work for the Ministries of Labour and Social Solidarity, Health and Education. They are responsible for: a) identifying children and families who are eligible for SNIPI; b) ensuring the care needed by children and families who, although not immediately eligible for SNIPI, require periodic evaluation; c) helping ineligible children and families who need social support; d) preparing and performing the individual EI plan for each child; e) identifying the needs and resources of the community, mobilizing formal and informal forms of support; f) working in collaboration, when appropriate, with the committee for the protection of children and young people and/or with other entities who work in the field of child protection; g) ensuring, when necessary, suitable transitions from the SNIPI to other programs, services or educational settings; and h) collaborating with kindergarten and nursery teachers (Decree-law No. 281/09, of October 6, 2009).

#### *Families of Children with Autism Spectrum Disorder*

Research in the area of ASD has sought to understand and explore its influence on families and on each family member, their functions and dynamics, as well as in their interactions with employment, leisure, the extended family, and the community. The majority of studies has demonstrated a relationship between ASD and the health of parents, both at the physical and psychological level, where it is possible to find high levels of depression, feelings of disbelief, pain, anxiety, guilt and anger, as well as low levels of physical and mental well-being (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Karst & Van Hecke, 2012).

Literature has shown that these families experience high levels of stress (Harper, Dyches, Harper, Roper, & South, 2013; Hoffman et al., 2009) which can be triggered by diverse factors. The most common triggers are a variety

of concerns related to the experience and care of the child with ASD, namely:

- The child's inappropriate and unpredictable behaviour (Hall & Graff, 2011),
- Problems regarding social and parental relationships with the child (Hoffman et al., 2009),
- The diagnostic process (Stuart & McGrew, 2009),
- Lack of knowledge and information regarding ASD (Stuart & McGrew, 2009),
- Overload of care regarding the child's needs (Harper et al., 2013),
- Concerns about the child's future and education (Dillenburg, Keenan, Doherty, Byrne, & Gallagher, 2010),
- Lack of and demand for various resources and social support (Dillenburg et al., 2010; Harper et al., 2013),
- Poor acceptance of the child with ASD by the extended family and community (Sullivan, Winograd, Verkuilen, & Fish, 2012), and
- Unmet needs (Dillenburg et al., 2010).

The characteristics associated with ASD cause major limitations in the functioning and the dynamics of the family system, as well as the interactions between children with ASD and their families. The lack of reciprocity and emotional involvement of the child, combined with family difficulties in responding to and comforting the child, greatly influence the quality of the interaction between parents and their children, resulting in a lower sense of parenting and parental competence (Hoffman et al., 2009; Karst & Van Hecke, 2012).

Simultaneously, changes in marital and family life, poor adaptability to the problem of raising a child with ASD, difficulties in family cohesion, and expressions of affection are common in these families (Harper et al., 2013; Nealy, O'Hare, Powers, & Swick, 2012).

Also, the relationship between parents and the siblings of children with ASD may be further compromised and neglected by the immense time and care that the child with ASD requires. Regarding these siblings, research shows that they feel neglected, alone and concerned about the future of the child with ASD, in comparison with siblings of typically developing children (Green, 2013).

Adherence to rigid and inflexible routines by the child, combined with the difficulty in accepting change, create numerous alterations in the family's routines and in the family's involvement in the community, implying several adaptations with respect to all members of the family (Lee, Harrington, Louie, & Newschaffer, 2008; Nealy et al., 2012). As a result, these families tend to isolate themselves from the contexts in which they live, choosing not to participate in activities with their extended family, recreational and leisure groups, and the rest of the community (Dillenburger et al., 2010). In such contexts, parents also referred to the great need to provide information and educate the community about ASD, in order to protect their children from prejudice and hostile behavior (Sullivan et al., 2012).

The care that children with ASD require implies a great expenditure of time and energy by families, causing alterations in family routines, including changes in family management and schedules, which also compromises future possibilities of job promotion (Lee et al., 2008; Nealy et al., 2012).

Most studies also report that there are grave concerns about the future of the child with ASD, depending on the child's development stage and the challenges that are posed to both child and family. Starting school and the transition from pre-school to primary education are a source of great concern for most parents (Dillenburger et al., 2010; Karst & Van Hecke, 2012).

Recent research has sought to understand and explore this topic among parents of children with ASD, making it possible to identify and categorize the main concerns felt by families, namely: (a) concerns associated with the diagnostic process (Siklos & Kerns, 2007); (b) economic concerns (Hall, 2012; Nealy et al., 2012; Siklos & Kerns, 2006); (c) concerns regarding the type, quality and functioning of available services and resources (Siklos & Kerns, 2007); (d) information requirements (Renty & Roeyers, 2006); (e) recreation and socialization needs (Nealy et al., 2012); and (e) unmet needs (Siklos & Kerns, 2006).

#### *Current Study*

Moreover, research has shown the importance of EI in the response to the concerns

of families of children with ASD (Reis, Pereira, & Almeida, 2014). The demand and implementation of support as early as possible for the child with ASD implies an increase in the concerns of the family system. Therefore, this step is essential to carry out intervention programs focused on child development and on responding to the concerns of families, by mobilizing support and helping the family adapt to the challenges and demands associated with caring for a child with ASD (Reis et al., 2014). However, research also shows that professionals have a tendency to focus intervention only on the child with ASD, while not appreciating the concerns and priorities of families (Bultas, 2012). Just a few Portuguese studies examined specifically the concerns and required supports of families of children with ASD. In the absence of enough research, this field has little understanding of the functioning and adequacy of formal and informal supports that are required for these families.

Therefore, the aims of this study were to: (1) identify and recognize the concerns of Portuguese mothers with children with ASD; (2) identify and recognize the required means of support those mothers need; and (3) understand the adequacy of the support networks given to these mothers, according to their concerns. As a result, three questions guided our work:

1. Which are the concerns of Portuguese mothers with children with ASD?
2. Which resources and supports do these mothers have access to?
3. How do these resources and supports operate, in face to these mothers' concerns?

To answer these questions, we followed a qualitative methodology study with 12 Portuguese mothers of children with ASD, ages 3 to 6 years old. The qualitative methodology adopted is in line with the questions guiding this investigation, considering the need for a more detailed, in-depth, individual and personal research, on a subject which research is emerging (Bogdan & Biklen, 1994).

## Method

### *Participants*

Participants were Portuguese mothers of children with ASD, ages 3 to 6 years old, enrolled in the SNIPI. These mothers are the family members who spend more time with the child, accompanying him/her in seeking and obtaining support (e.g., medical and therapeutic support; schooling; access; transport and monitoring services and resources; basic care). Exclusion criteria included mothers of children with other developmental disorders besides ASD and/or children without a formal diagnosis of ASD.

After requesting the collaboration of an institution specialized in supporting families and children with ASD, 20 mothers who fulfilled the inclusion criteria were individually asked to participate in the study. The 12 mothers who consented to participate signed an informed consent. All of these mothers lived in the same urban district and were supported by an institution that is specialized in supporting families and children with ASD, with two psychologists, two speech therapists, two occupational therapists, one child psychiatrist and one social worker. This team gave EI support, although it did not belong to the SNIPI.

Following, participants were contacted by telephone by the investigator to schedule the interviews at a time chosen by each mother. All the interviews were carried out in the institution where the families and their children are supported, in a room familiar to the participants, in order to ensure a safe and non-threatening natural context for the mothers and to create an environment favorable to share information (Bogdan & Biklen, 1994).

The selection of mothers was performed according to an intentional selection criterion, by integrating subjects we considered to be an asset to the collection of as much relevant information as possible to the subject and study objectives (Patton, 2002). The mothers were selected in series, taking into account the data obtained with the above mentioned subject, and looking for different information and/or clarifying certain aspects with the following subjects.

### *Data Collection Instrument*

The instrument used to collect data was a single semi-structured interview. Previously, the preparation of a preliminary interview guide was made, followed by its validation. This validation included the interview of a mother followed by an in-depth analysis by a specialist in qualitative research. This process provided a review of the content and form of the questions, the language that was used, as well as the effectiveness of the interview script, in light of the purposes of the research. Finally, we achieved a final guide with a set of open-ended questions in a sequence that was appropriate to the study objectives (Kvale, 1996).

Each interview began with the presentation of relevant information concerning the subject and the objectives of the study. The first three questions were focused on bringing the mothers to the main themes, and also, on fostering an empathic and friendly atmosphere to their participation (Kvale, 1996). Then, specific direct questions were made to search for data related to the study phenomenon, in a flexible way, according to the course of the interview. Whenever necessary, follow-up questions, probing questions, indirect, structuring and interpreting questions were performed (Kvale, 1996). Interviews were completed with a brief summary of the main information obtained, giving opportunity for mothers to add information and/or request clarification concerning any possible doubts (Kvale, 1996). All the interviews were performed by one same investigator, and each took about 45 minutes. Data was collected using a digital recorder, and later on transcribed and computerized by that investigator.

### *Data Analysis*

All data from interviews was converted into a single data file. First, these transcripts were read by the investigator to create the material for analysis, and emergent categories were created using deductive and inductive methods (Bardin, 2009; Lima, 2013). To ensure the material's reliability and validity, two coders, both familiar and holding theoretical and practical knowledge about ASD, coded the

TABLE 1

Category System

1. Concerns of the mothers
2. Support for the mothers
2.1. Formal support
2.2. Informal support
3. Adequacy of the forms of support in light of the concerns of the mothers
3.1. Formal support response
3.2. Informal support response

data independently of the categories defined by the investigator.

The percentage agreement index (i.e., number of agreements divided by number of agreements plus disagreements and multiplied by 100) was used to calculate intercoder agreement. According to some authors, agreement percentages above 80% are considered good indicators of reliability, although others point more demanding values, such as 85% (Coutinho, 2011). The calculated percentage showed a substantial rate of agreement, as we obtained an intercoder reliability above 80 (89.79%) (Krippendorff, 1980; Lima, 2013). Therefore, a final coding was performed, organizing the units in different categories and subcategories.

Results

The presentation of the results was carried out taking into account the research's empirical questions, and the category systems taken from the content analysis of the research data (Bardin, 2009; Bogdan & Biklen, 1994).

Concerns of the Mothers

Mothers mentioned concerns at different times of their lives and, especially, the lives of their children. These concerns were related to their own child, the family system, and broader aspects such as the social and economic environment.

The most common difficulties mentioned by the mothers were the child's lack of speech and eye contact. Participants reported that these concerns appeared when their children were 18 months. Three mothers referred the presence of restrictive and repetitive behavior,

interests and activities. For example, one mother said, "he was constantly fascinated with the washing machine".

Most mothers highlighted the presence of feelings of anxiety, shock, guilt and non-acceptance of the diagnosis of ASD, especially after its confirmation. One mother described her feelings in this way: "it's so difficult and hard . . . later, you blame yourself because you think it's your fault, you didn't do things correctly or, in the past you did something and now, you are being punished. So you ask yourself why? Why was I chosen to have a child with this problem?".

However, a minority of participants shared a different view regarding the diagnosis. For example, a mother said "we don't see ourselves in another situation. For us, it's already normal (. . .) More work? Yes! But at this moment, we don't see ourselves in another situation". Another mother said that the diagnosis gave her a new vision about her own life and the resolution of some problems: "Now it's like this: I now have my own things to think about. Things we used worry about before, are no longer important".

Some mothers said they had concerns and expectations regarding their child's development and future, especially about his/her autonomy and future care in the event of the death of a parent. For example, one mother said, "the future worries me. . . . what's he going to do when I die? Who will take care of him?"

The majority of mothers said they had needed information about ASD when they first received the diagnosis, as one mother said, "when I was told that my child had autism, I asked, "what's that?". I didn't know nothing about that". Mothers also mentioned the need for information regarding the necessary support available after the initial diagnosis: "At first, I asked some questions and doctors were not very clear. I had many doubts . . ." and "another thing I didn't like was that when I was given the diagnosis, I was left on my own".

Half of the mothers said they had many concerns related to the daily functioning of the child, as one mother explained: "There is always a battle: the pacifier, the tantrums, mood swings, now it's a battle with potty training . . .there are always challenges . . .".

T1



The majority of mothers shared their concern and anxiety regarding the transition to the 1<sup>st</sup> year of school: “He still has one year and a half before starting primary school. If only he could communicate and integrate more even if he doesn’t speak . . .”. Another mother said: “My fear is when he goes to school. Will he be treated badly? Will they hurt my child?”

The burden of care was a concern shared by half of the participants. One mother stressed: “And then I do nothing! I am always with my son running from one place to the other. That’s my life”. Some mothers spoke about the difficulties in reconciling their professional life with the role of parenting a child with ASD. Here, some mothers said: “I can’t come more often to therapeutic services. Our jobs don’t allow us that, unfortunately”, “I think that mothers do not have the chance to hold a full-time job and, at times, we have to hide this fact in order to get a job”.

Mothers reported the need for psychological support, especially after the diagnosis. For example, one mother said: “I think there should be more support like psychological help for parents because having a child with ASD is a big blow”. These mothers highlighted the importance of psychological help, not only for the couple, but also for the entire family.

### *Support for the Mothers*

Mothers described a wide range of formal and informal supports that were sought based on their main concerns and priorities, and at different times of the child’s life and of the family’s life phase.

*Formal support.* In the initial phase and during the diagnostic process, most mothers turned to doctors from different specialties: general practice and family medicine, pediatrics, developmental pediatrics, and child psychiatry. Currently, all mothers report having support from a general practitioner and family doctor, a pediatrician, a developmental pediatrician and /or a child psychiatrist. All children have therapeutic support, which may include one or two of the following areas: psychology, speech therapy, and occupational therapy. The vast majority of parents became aware of these forms of support through de-

velopmental pediatricians or child psychiatrists.

All mothers reported that their children attend kindergarten at the time. The vast majority of families are supported by EI local teams. Five mothers learned about the support of the SNIPI through the kindergarten teacher, while the remaining mothers were informed by the developmental pediatrician or child psychiatrist, after the ASD diagnosis was confirmed.

*Informal support.* Most mothers said they could count on current family support. It is also noted, however, that this support corresponds only, in most cases, to the family nucleus (spouse and siblings), as one mother said “Support comes from the home, us three”. One mother said that she only could count on the spouse (“It is only me and my husband. Apart from us, there is no one else”), while three mothers highlighted the support from the siblings (“My daughter just naturally helps . . . if someone tries to speak to him and asks why he doesn’t speak”).

Taking into consideration the responses of mothers, it appears that only a few families have resorted to informal support in the initial time of diagnosis. Only two mothers emphasized the importance of the support given by other parents of children with ASD in their daily lives. One participant mentioned receiving parent to parent support.

As a result, the Internet is the informal support most used by these mothers before and during diagnosis process. First, mothers wanted to search for information and clarify doubts about the early warning signs they identified in their children. At this level, one mother highlighted “Searching on the Internet started more or less at that time, between 1 [½] and 2 years of age. I typed in some signs that my child was showing and the word Autism appeared”. After the diagnosis, mothers searched on the internet for information about the diagnosis and about the formal support available for their children. One participant highly appreciates this support today, saying “I speak to Google, my best friend (. . .) I read a lot of things on the Internet. I also read a lot of things from other parents who talked about what they did and this gave me some ideas”.

### *Adequacy of the Forms of Support in Light of the Concerns of the Mothers*

**Formal support response.** Regarding the initial response of formal support, some mothers stated that their concerns were deemphasized or devalued by doctors of the medical specialties of general practice and family medicine and pediatrics. One mother mentioned “When he was 18 months old, I spoke with a pediatrician but all he said was that my child was slightly behind but he was smart . . . there was nothing wrong with him”. Only three mothers mentioned the appreciation of the initial concerns by doctors of the medical specialties of the medical specialties of general practice and family medicine, and pediatrics.

Three mothers also mentioned the value of the initial concerns on the part of kindergarten teachers, even for specialized medical support: “The kindergarten teacher spoke with another mother who was a nurse and who got me a consultation in the hospital because my husband’s family doctor refused to see my child or have her as his patient”.

About the adequacy of formal support in the diagnostic process, three mothers stated that the process leading to the diagnosis is complex and time consuming, and highlighted the following aspects. The waiting time for a consultation in the pediatric development specialty in a public hospital was very long: “Because we have had to wait so long for a consultation, my daughter was already three when she finally attended a pediatric development consultation . . . I have had my suspicions since she was two . . .”. The process involved in getting a consultation and carrying out exams necessary to reach a diagnosis is extremely time-consuming. These delays generate difficulties in accessing therapeutic and educational support. Some mothers mentioned that, at the beginning and during the diagnosis process, doctors need to be better informed about existing therapeutic, educational and social support. As one mother said, “They should be a little more prepared, at least with the basics and, later, help guide us in the right direction”.

Half of the families who participated in this study said that the family has to be proactive in seeking and accessing the therapeutic, educational and social support they need: “I was the

one who had to make phone calls, look up on the Internet, and started asking questions because when we get the diagnosis, we are left on our own. That’s what we’ve got and each one has to survive”.

Most mothers referred to the adequacy of responses of medical specialties in the area of child psychiatry and developmental pediatrics in relation to the family’s concerns. These opinions relate mostly to the period prior to obtaining the diagnosis and to the present day, with one mother adding, “There is always someone there who is willing to help us get through this difficult time”.

In relation to the adequacy of formal support to the family’s current concerns, all participants mentioned the appropriateness of current medical and therapeutic support. One mother said, “I owe them everything, even the change in our lifestyle”. However, although they feel supported, some mothers would like to have more frequent and long therapeutic support sessions. Regarding support from the EI local team, seven mothers considered the support they received to be adequate in relation to their concerns.

**Informal support response.** The opinion regarding the appropriateness of informal support in different periods of the life of the child and family was different. At the beginning, three mothers said their extended families devalued the early warning signs identified by parents. One mother said, “My family thought that it was something I had invented in my head”. Currently, most participants expressed satisfaction with the support provided from the household, including just the spouse and siblings. Regarding the extended family and friends, mothers considered that these supports do not fulfill their needs. One mother said, “I’m talking about the grandparents. They accept my child the way she is, but if they could avoid being with her, they would” and “In our situation, all our friends accept him but when it comes to help, they don’t help that much”.

## **Discussion**

### *Summary of Findings*

Research in ASD has demonstrated the importance of early diagnosis and intervention fo-

cusing on the child and the family, and on the development of interdisciplinary answers (Gabovitch & Curtin, 2009; Reis et al., 2014). In this sense, international research has been attempting to understand the concerns of families of children with ASD and the forms of support they have access to (Hall & Graff, 2010, 2011; Siklos & Kerns, 2006). However, scientific research at the level of family centered practices in families of children with ASD is still emerging (Gabovitch & Curtin, 2009).

Findings from this investigation enhance our understanding about the perception of these families, regarding the adequacy and effectiveness of answers given by the services and supports, taking into account the concerns and priorities of the mothers of children with ASD.

Based on the qualitative data produced by this investigation, it appears that most of the concerns of the participants are expressed by most of the scientific studies in this area (Siklos & Kerns, 2006, 2007). In the initial moments, the first concerns correspond to the identification of developmental warning signs in children by the family. The absence of speech and eye contact, and the presence of unusual behavior, restricted and repetitive interests and activities compromise the process of communication between parents and the child, generating feelings of frustration and the perception of a lack of parenting competence, which is discussed in literature (Hall & Graff, 2010; Hoffman et al., 2009). After confirmation of the diagnosis of ASD, we found that the concerns increased and were no longer just child-centered, but involved the entire family and all family contexts, as is evidenced by the results by Nealy et al. (2012), and Stuart and McGrew (2009).

Data collected in this study shows that these mothers rarely resort to informal forms of support, which is contradictory to most studies in EI (Hall & Graff, 2010; Trivette, Dunst & Hamby, 2010). Also, families seem to invest more in the family nucleus, as the informal support networks are often limited to the spouse and the siblings. The low demand for broader informal support suggested by this study appears to be related to the inadequacy of informal support in relation to the concerns of mothers, since family members (grandparents, as well

as other relatives and friends) have difficulty in accepting the ASD situation and are unaware of its existence, and/or avoid dealing with a child with ASD. We also found that these mothers rely very little on friends, parent groups and other parents of children with ASD, in what appears to be a voluntary protective option aimed at avoiding judgmental and prejudicial opinions from friends and family, as well as the result of the difficulty in sharing intimate information (Hall & Graff, 2011; Sullivan et al., 2012).

The inadequacy of formal and informal support means that some mothers are proactive in seeking and accessing support. Mothers attributed this need in large part to the lack of information given by the formal supports, mainly during the diagnostic process. These data provide important findings about the importance attached to the Internet by these mothers, which is the most used form of informal support to obtain information and to clear up doubts about the diagnosis of ASD and the forms of support that are available to the child, as shown in some studies (Zaidman-Zait & Jamieson, 2007). The major drawback found in this theme refers to the quantity and quality of information available on the Internet for parents who are at an early stage of acceptance and understanding of ASD, and who do not know yet how to discriminate the information correctly, which may pose a danger and raise their concerns and questions.

Furthermore, the Internet may not always have the right answers that parents seek or, on the other hand, it may provide more information than the family can handle, at an emotional level, which may have adverse effects on the parents' perception regarding the prognosis and the future of their child and of the family itself.

Most mothers search for and give greater value to more formal support throughout the life of the child with ASD. It appears that there is a great demand for formal support, especially at the initial phase of diagnosis, and it is inversely proportional to the satisfaction levels and perceptions of the adequacy of these same supports. Such perceptions of mothers can be understood in light of the undervaluing and postponement they felt regarding their concerns from doctors. The diagnostic process is complex and time-consuming, leading to late referral and access to services and



specific supports for children with ASD and their families.

The multiple findings that emerged from the participants' speech concerning the diagnosis of children with ASD do not reflect the directions derived from research, which stress the priority and advantages of an adequate signaling of children with ASD and early intervention, namely: (a) access to specialized information for parents, addressed to their specific concerns; (b) the possibility of preventing the most serious and complete manifestations of ASD by making use of the plasticity of the brain in the early stages, and also, behaviour changes that can be potentially accomplished by EI; and (c) the possibility of achieving gains in terms of adaptive and cognitive functioning of children with ASD that ultimately may decrease the concerns of these families (Reis et al., 2014; Zwaigenbaum et al., 2013).

Mothers reported the adequacy of recent formal supports (EI local teams and therapeutic support). Nevertheless, they criticize the amount of support, its frequency and the duration of the sessions provided. These findings show that the inadequacy of this support is primarily directed to national policies, more specifically, the way they are implemented and the quality of the procedures and measures available to children with special needs and their families in Portugal.

Ultimately, according to the Decree Law No. 281/09 of October 6 (2009), the SNIPI should be based on universal access, accountability and responsiveness of professionals and public entities, with benefits that shall be greater as earlier necessary support is given to the family and the child. The legislation shows a concern to ensure a system of interaction between families and institutions and, primarily, the health system, so that all children and families are properly identified and flagged as quickly as possible. However, professional practice shows us a different reality, where the implementation and applicability of the principles fall short of what is advocated and recommended in the theoretical and legal frameworks. Therefore, it is essential to promote cooperation and coordination between policies and practices, in order to analyze and assess the responsiveness and quality of the

support that is given to families of children with ASD.

### *Study Limitations*

Qualitative research requires that researchers have training and experience and are capable of performing a wide range of different techniques concerning qualitative methodology and semi-structured interviews. Despite the constant effort to perform procedures conferring validity, reliability and scientific rigor to this study, we are aware of the presence and influence of some limitations that will be discussed below.

Firstly, the large number of interviews and consequent volume of data made content analysis and interpretation time consuming. Beyond this reality, it is likely that some procedures related to content analysis, particularly the definition of units, as well as coding categories, may have been influenced by our personal and professional experience, as well as knowledge and beliefs about the subject.

Secondly, this study adds important considerations in terms of the adequacy of the support that is given to these families. However, we consider that there is still much to explore about this topic and, perhaps, the third research question we posed may have been too ambitious for what the study could answer. Furthermore, the 3 to 6 year old age span is, possibly, too wide, during which the concerns and the developmental and contextual demands for children with ASD change quite a bit. The selection of a more narrow age group could have been more appropriate.

Even in conceptual terms, the word "support" was not entirely clear to these families. In fact, for some participants, if a determined form of support did not meet their concerns and priorities, it was no longer considered "support". Given the conceptual difficulty, in some interviews, it was necessary to define and clarify the designation of "support", to ensure adjusted and detailed data, according to the interview questions.

Thirdly, we would like to mention the fact that the 12 mothers belong to a single geographic region and are mostly supported by the same entities that guarantee medical, therapeutic and educational support. This may

justify the uniformity of some of the results and experiences shared by families with regard to the adequacy of existing formal supports.

#### *Future Research Recommendations*

Considering the increasing prevalence of ASD and the insufficient amount of research in terms of a family-centered approach in the field of this disorder, we believe that there are still many paths to be discovered and created by the scientific community. This reality reinforces the need to perform further studies in this field, towards the development and implementation of strategies and practices that are increasingly tailored to the concerns and priorities of these families.

In order to achieve a broader picture of the situation of families of 3 to 6 year-old children with ASD, we recommend the development of a mixed research with a larger number of families. In this case, it would be important to include the fathers of children with ASD, to examine their perceptions about the concerns, the forms of support that families have access to, and their adequacy in light of the concerns of families. Also, the establishment of a focus group with participants would be recommended, to carry out more focused interviews, which would help to better understand the experiences and opinions of the families from an in-depth perspective.

The main findings from this study add an important insight for health professionals and the practices of early interventionists. Firstly, these results indicate an increased demand for formal support throughout the life of the child with ASD at the expense of informal support. At the same time, families refer to the inadequacy of this form of support at certain times, which is corroborated by several studies in the field of ASD (Minnes & Steiner, 2009; Renty & Roeyers, 2006). Further research is, therefore, essential to understand why current formal supports are inadequate and to cast some light on which procedures may be included, removed or altered so that the concerns, priorities and expectations of families are met.

Considering the new findings obtained in this study related to informal supports, it is

relevant to research and understand parental expectations more deeply, as well as formats of search and access to, and also, the adequacy and effectiveness of, the informal support that are available to these families. These findings are an asset to the EI professionals to: (a) have more knowledge and raise awareness about the difficulties experienced by families; (b) seek early referral to appropriate support (Siklos & Kerns, 2007); (c) assist families in building solid support networks, when such support lacks or is insufficient (Hall & Graff, 2010); and (d) assist in the coordination between the various sources of support (Renty & Roeyers, 2006).

Another area for future research consideration concerns the development and concrete definition of procedures and preventive measures at the level of EI in Portugal, which are focused on raising awareness and training of professionals in primary health care (general practice and family medicine and pediatrics), and who are the first these families resort to looking for support.

A chance to put these measures and preventive strategies in practice may entail that EI local teams access more directly and quickly to the medical system. Conducting information sessions and workshops to families and doctors of primary health care, as well as regular meetings with these professionals and early interventionists, could be helpful to improve, enhance and accelerate the signaling process of these children.

It is considered that principles and procedures for the evaluation and support of families of children with ASD, even if involved and guided by a family-centered approach, present specific features which should be targeted for recognition, consideration and analysis by medical, therapeutic and educational entities, as well as by existing political entities. It seems that there is a gap between what the law states and hopes to accomplish, and what is done in the field. Therefore, evidence-based studies and further research with families and professionals must be done, in order to explore what is happening in the field of EI in Portugal, as well as the effective fulfillment of the goals advocated by the SNIPI.

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Received: 19 June 2016  
Initial Acceptance: 23 August 2016  
Final Acceptance: 10 October 2016

## AUTHOR QUERIES

**AUTHOR PLEASE ANSWER ALL QUERIES**

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